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Patient #: __ __ __

Application Date: __ __ __

Screening and Natural History of Patients with Fibrous Dysplasia and the McCune - Albright Syndrome

Patient's Information

Last Name [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

First Name [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Middle Name [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Street [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

City [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

State [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Zip Code [ ][ ][ ][ ][ ][ ][ ][ ][ ]

Country [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Home Number (Country Code) [ ][ ][ ][ ]-(Area Code/City Code) [ ][ ][ ][ ]-(Number) [ ][ ][ ][ ][ ][ ][ ][ ][ ]

Work Number [ ][ ][ ][ ]-[ ][ ][ ][ ]-[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Fax Number [ ][ ][ ][ ]-[ ][ ][ ][ ]-[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

E-mail [ ]

Date of Birth [ ][ ]-[ ][ ]-[ ][ ]
mo day yr

Gender [ ] male [ ] female

Race [ ]American Indian or Alaskan Native
[ ] Asian or Pacific Islander
[ ] Black [ ] Hispanic [ ] White

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Doctor's Information

Last Name [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

First Name [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Street [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

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Zip Code [ ][ ][ ][ ][ ][ ][ ][ ][ ]

Country [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

(Country Code) (Area Code/City Code) (Number)

Home Number [ ][ ][ ][ ][ ]-[ ][ ][ ][ ][ ]-[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Work Phone [ ][ ][ ][ ][ ]-[ ][ ][ ][ ][ ]-[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Alt Phone [ ][ ][ ][ ][ ]-[ ][ ][ ][ ][ ]-[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Fax Number [ ][ ][ ][ ][ ]-[ ][ ][ ][ ][ ]-[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Email [ ]

Specialty [ ]

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Fibrous Dysplasia History

1. When were you diagnosed with FD? [ ] / [ ] / [ ]

2. What were the symptoms at the time?
(check all that apply)

[ ] pain	[ ] fracture	[ ] deformity
[ ] limp	[ ] swelling	[ ] abnormal growth
[ ] visual or hearing loss	[ ] headache	[ ] none

3. How was the diagnosis made?
(check all that apply)

[ ] x-ray

[ ] CT

[ ] MRI

[ ] bone scan

[ ] medical history (for example: bone disease in the setting of MAS)

[ ] biopsy

[ ] other, explain:

_____

_____

_____

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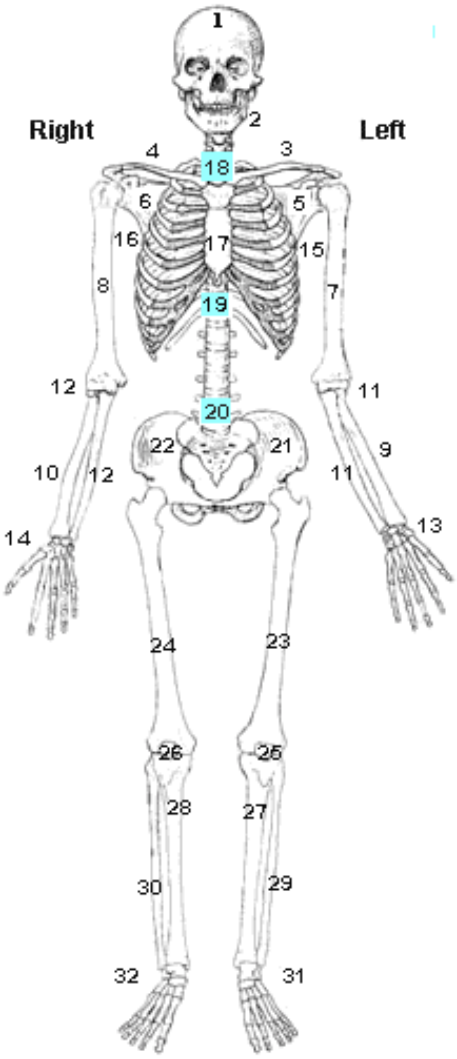
4. What bones were involved at the time of diagnosis? Indicate on the skeleton by marking with an 'X'.



[ ] 1.Skull
[ ] 2.Mandible (Jaw)
[ ] 3.Left Clavicle (Collar bone)
[ ] 4.Right Clavicle (Collar bone)
[ ] 5.Left Scapula (shoulder blade)
[ ] 6.Right Scapula (shoulder blade)
[ ] 7.Left Humerus (Upper arm)
[ ] 8.Right Humerus (Upper arm)
[ ] 9.Left Radius (Forearm)
[ ] 10.Right Radius (Forearm)
[ ] 11.Left Ulna (Forearm)
[ ] 12.Right Ulna (Forearm)
[ ] 13.Left Hand/Wrist
[ ] 14.Right Hand/Wrist
[ ] 15.Left Ribs (1-12)
[ ] 16.Right Ribs (1-12)
[ ] 17.Sternum (breast bone)
[ ] 18.Cervical Spine (Neck)
[ ] 19.Thoracic Spine
[ ] 20.Lumbar spine (lower back)
[ ] 21.Left Pelvis
[ ] 22.Right Pelvis
[ ] 23.Left Femur (Thigh)
[ ] 24.Right Femur (Thigh)
[ ] 25.Left Patella (knee Cap)
[ ] 26.Right Patella (knee Cap)
[ ] 27.Left Tibia (Lower leg large bone)1
[ ] 28.Right Tibia (Lower leg large bone)1
[ ] 29.Left Fibula (Lower leg small bone)
[ ] 30.Right Fibula (Lower leg small bone)
[ ] 31.Left Foot/Ankle
[ ] 32.Right Foot/Ankle

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5. Did you have symptoms prior to the diagnosis?

[ ] yes [ ] no [ ] Not Available
(if no, go on to question 6)

When did you first have symptoms (approximate date)?

Date: [ ] / [ ] / [ ]

What were the symptoms?

[ ] pain	[ ] fracture	[ ] deformity
[ ] limp	[ ] swelling	[ ] abnormal growth
[ ] visual or hearing loss	[ ] headache	[ ] limb discrepancy

What were your earliest symptoms?

[ ] pain	[ ] fracture	[ ] deformity
[ ] limp	[ ] swelling	[ ] abnormal growth
[ ] visual or hearing loss	[ ] headache	[ ] limb discrepancy

6. What are your current symptoms?

[ ] pain	[ ] fracture	[ ] deformity
[ ] limp	[ ] swelling	[ ] abnormal growth
[ ] visual or hearing loss	[ ] headache	[ ] none

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7. Do you, or have you taken medicines for pain?

Drug Name	Frequency (see explaination below)	Month/Year Started	Month/Year Stopped	Effectiveness
	[ ] rarely [ ] occasional [ ] regularly [ ] daily			[ ] not at all [ ] somewhat [ ] complete
	[ ] rarely [ ] occasional [ ] regularly [ ] daily			[ ] not at all [ ] somewhat [ ] complete
	[ ] rarely [ ] occasional [ ] regularly [ ] daily			[ ] not at all [ ] somewhat [ ] complete
	[ ] rarely [ ] occasional [ ] regularly [ ] daily			[ ] not at all [ ] somewhat [ ] complete
	[ ] rarely [ ] occasional [ ] regularly [ ] daily			[ ] not at all [ ] somewhat [ ] complete
	[ ] rarely [ ] occasional [ ] regularly [ ] daily			[ ] not at all [ ] somewhat [ ] complete
	[ ] rarely [ ] occasional [ ] regularly [ ] daily			[ ] not at all [ ] somewhat [ ] complete
	[ ] rarely [ ] occasional [ ] regularly [ ] daily			[ ] not at all [ ] somewhat [ ] complete

Explanation of Frequency:

Rarely = 1 or 2 times a month
Occasional = 1-2 times a week
Regularly 3 - 6 times a week
Daily = 1 or more times daily

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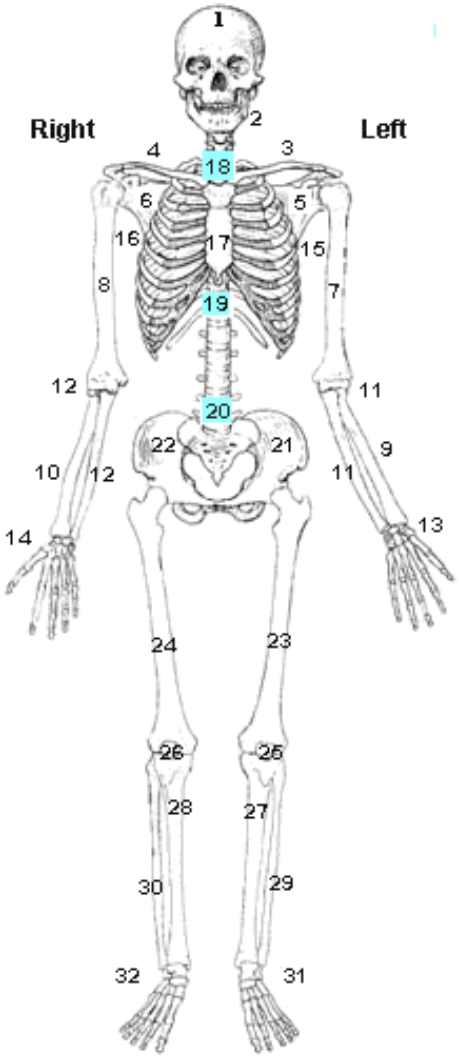
8. Have you had any fractures?

[ ] yes [ ] no

If so, Indicate sites on attached skeleton. Number the fractures sequentially. That is, the first fracture you had is number 1, the second number 2, etc. If you have had multiple fractures at a site, indicate it. For example, one site may be fracture number 3 and 5.



[ ] 1.Skull _____
[ ] 2.Mandible (Jaw) _____
[ ] 3.Left Clavicle (Collar bone) _____
[ ] 4.Right Clavicle (Collar bone) _____
[ ] 5.Left Scapula (shoulder blade) _____
[ ] 6.Right Scapula (shoulder blade) _____
[ ] 7.Left Humerus (Upper arm) _____
[ ] 8.Right Humerus (Upper arm) _____
[ ] 9.Left Radius (Forearm) _____
[ ] 10.Right Radius (Forearm) _____
[ ] 11.Left Ulna (Forearm) _____
[ ] 12.Right Ulna (Forearm) _____
[ ] 13.Left Hand/Wrist _____
[ ] 14.Right Hand/Wrist _____
[ ] 15.Left Ribs (1-12) _____
[ ] 16.Right Ribs (1-12) _____
[ ] 17.Sternum (breast bone) _____
[ ] 18.Cervical Spine (Neck) _____
[ ] 19.Thoracic Spine _____
[ ] 20.Lumbar spine (lower back) _____
[ ] 21.Left Pelvis _____
[ ] 22.Right Pelvis _____
[ ] 23.Left Femur (Thigh) _____
[ ] 24.Right Femur (Thigh) _____
[ ] 25.Left Patella (knee Cap) _____
[ ] 26.Right Patella (knee Cap) _____
[ ] 27.Left Tibia (Lower leg large bone)1 _____
[ ] 28.Right Tibia (Lower leg large bone)1 _____
[ ] 29.Left Fibula (Lower leg small bone) _____
[ ] 30.Right Fibula (Lower leg small bone) _____
[ ] 31.Left Foot/Ankle _____
[ ] 32.Right Foot/Ankle _____

9. Indicate how each fracture was treated.

Conservative => casting, non-weight bearing, crutches, bracing, partial weight bearing

Location	Conservative	Surgical	Date
	[ ]	[ ]	
	[ ]	[ ]	
	[ ]	[ ]	
	[ ]	[ ]	
	[ ]	[ ]	
	[ ]	[ ]	
	[ ]	[ ]	
	[ ]	[ ]	
	[ ]	[ ]	

10. Have you had any spinal problems?

[ ] scoliosis (curvature of the spine)
[ ] kyphosis (hunch-back) [ ] Vertebral Fracture
[ ] Low Back Pain [ ] other, explain: _____
[ ] none

11. Have you had any neurological complications from your FD?

[..] decrease or loss of vision
[ ] decrease or loss of hearing [ ] Muscle weakness - body
[ ] Muscle weakness -face [ ] Sensory [ ] None

12. Have you been diagnosed with ostemalacia? [ ] yes [ ] no

13. Have you been diagnosed with low blood phosphorus? [ ] yes [ ] no

14. Have you been diagnosed with high urinary phosphorus? [ ] yes [ ] no

15. Have you been diagnosed with kidney stones? [ ] yes [ ] no

16. Do you have a problem with blood clotting? [ ] yes [ ] no

17. Do you have a problem with excessive bleeding or easy brusing? [ ] yes [ ] no

18. Have you ever required a transfusion? [ ] yes [ ] no

19. Do you have any craniofacial deformity? That is, is the shape of your face or head abnormal?

    [ ] yes [ ] no

20. Do you have any dental abnormalities?

    [ ] yes [ ] no

21. Do you have a discrepancy in the length of your legs and arms?

    [ ] right leg longer than left [ ] left leg longer than right
    [ ] right arm longer than left [ ] left arm longer than right
    [ ] no discrepancy

22. Have you had any other problems in your life, past or present, related to or as a result of your FD?

[ ] inability to engage in athletics, since what age _____
[ ] difficulty walking, since age _____
[ ] walk with crutches/cane, since what age _____
[ ] use ambulator, since what age _____
[ ] use wheelchair, since what age _____
[ ] wheelchair bound, since what age _____
[ ] difficulty performing activities of daily living, since age _____
activities of daily living = bathing, eating, combing hair, etc.

23. What was your age when you started puberty? _____

24. Was there any change (improvement or worsening) in your bone disease with around puberty status? From the list below please indicate wether the symptom got better, worse or had no change.

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

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(if you are male, go on to next page)

25. Have you entered menopause?

[ ] yes [ ] no
What age did you begin menopause? _____

What caused your menopause to begin

[ ] natural (spontaneous)
[ ] the result of surgery

If surgical, were your ovaries removed?

[ ] yes [ ] no

[ ] the result of chemotherapy
[display only if above checked]
If chemotherapy, for what reason was it received?

_____

Was there any change (improvement or worsening) in your bone disease with menopause? From the list below please indicate wether the symptom got better, worse or had no change.

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

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McCune-Albright Syndrome History

1. Have you been diagnosed with the McCune-Albright syndrome (MAS)?

   [ ] yes [ ] no

2. Do you have café-au-lait spots (or birthmarks) areas of darkened skin, the color of coffee with cream in it)?

   [ ] yes [ ] no

   Do the café-au-lait spots have smooth or irregular borders?

   [ ] irregular [ ] smooth

   How many spots did you have at birth _____?

   How many spots do you have now _____?

   Have the size of the spots
   [ ] increased [ ] decreased [ ] remained the same

   Which side of your body are the majority of your café-au-lait spots?

   [ ] right [ ] left [ ] fairly equal

   Is there any correlation between the side of your body on which most of your café-au-lait spots are and your FD? That is, is there a relationship between the side of your body which has the most café-au-lait spots and the side which has the most FD? Are they on the same or opposite sides?

   [ ] no relationship [ ] same side [ ] opposite sides

3. Do you or did you have precocious puberty? The signs of precocious puberty are:

in girls before 7 ½ years-of-age:vaginal bleeding, hair in the pubic area or armpit, body odor, breast development

in boys before 9 ½ years-of-age: lengthening of the penis, body odor, hair in the pubic area or armpit, aggressive or inappropriate sexual behaviour

[ ] yes [ ] no

At what age did the precocious puberty start: _____

What type of therapy or therapies (medicines and/or surgeries) for the precocious puberty in the past?

[ ] Medical [ ] Surgical [ ] None

4. Do you currently have precocious puberty?

[ ] yes [ ] no (proceed to next question)

What type of therapy are you currently on for this condition?

[ ] Medical [ ] Surgical [ ] None

Is it effective at controling the symptoms of precocious puberty?
[ ] yes [ ] no

5. At what age did you start puberty:_____

Puberty starts with breast development and/or development of pubic hair in girls (normally age 8-13) and with pubic hair and/or enlargement of the testes and lengthening of the penis in boys (normally age 9-14 years).

Was there any change (improvement or worsening) in your bone disease with or around the start of your puberty? From the list below please indicate wether the symptom got better, worse or had no change.

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

6. Do you have thyroid disease?

[ ] yes [ ] no [ ] never tested
(if no go on to question 7)

If yes, at what age did it start? _____

What is the nature of your thyroid disease?

[ ] hyperthyroidism (elevated thyroid function)

[ ] hypothyroidism (low thyroid function)

[ ] benign thyroid nodule(s)

[ ] thyroid cancer

Have you received any treatment for your thyroid disease?

[ ] Medical [ ] Surgical [ ] None

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Was there any change (improvement or worsening) in your bone disease with the onset of your thyroid disease? From the list below please indicate whether the symptom got better, worse or had no change.

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

Was there any change (improvement or worsening) in your bone disease during the treatment of your thyroid disease?.

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

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7. Have you been diagnosed with hypersecretion of any pituitary hormones? That is high growth hormone (causing acromegaly), high prolactin, high ACTH (causing Cushing's disease), high thyroid stimulating hormone (causing hyperthyroidism)?

[ ] yes [ ] no [ ] Don't Know

If yes, which hormone(s)?

Hormone	Age started	Treatment
[ ] growth hormone	_____	_____
[ ] prolactin	_____	_____
[ ] ACTH	_____	_____
[ ] TSH	_____	_____

What did the elevation of the hormone have you your bone disease? From the list below please indicate whether the symptom got better, worse or had no change.

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

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8. Have you been diagnosed as having elevated secretion of hormone(s) from the adrenal gland (cortisol, aldosterone)? Elevated secretion of cortisol causes Cushing's disease and elevated secretion of aldosterone causes severe hypertension with low potassium.

Hormone	Age diagnosed	Treatment
[ ] cortisol	_____	_____
[ ] aldosterone	_____	_____
[ ] None		

If yes, what effect did the elevation of the hormone have on your bone disease?

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

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9. Have you been diagnosed as having an elevation of parathyroid hormone? Elevations of this hormone cause elevations in your blood calcium (hypercalcemia).

   [ ] yes [ ] no
   (if no, go on to question 10)

   What age was it diagnosed: _____.

   What type of treatment was provided:
   _____

   What effect did it have on your bone disease symptoms?

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

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10. Have you been diagnosed as having hypophosphatemia (low levels of phosphate in your blood)?

[ ] yes [ ] no [ ] never tested/don't know
(if no, go on to question 11)

What age was it diagnosed: _____.

What type of treatment was provided:
_____

What effect did it have on his/her bone disease symptoms?

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

11. Have you been diagnosed as having rickets or osteomalacia?

[ ] yes [ ] no [ ] never tested/don't know

12. Do you have or ever had low vitamin D?

[ ] yes [ ] no [ ] never tested/don't know

13. Do you have any renal problems?

[ ] nephrolithiasis
[ ] proteinuria
[ ] aminoaciduria
[ ] calciuria
[ ] phosphaturia
[ ] insufficiency
[ ] hyperfiltration
[ ] none

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Fertility Questions

(if you are male, go on to next page)

14. Have you ever been pregnant?

    [ ] yes [ ] no
    (if no, go on to question 15)

    How old were you, when you got pregnant?
    (if more than once list them all separated by commas)
    _____

15. Do you have children?

    [ ] yes [ ] no

    List the age you were at each delivery:
    _____

16. Have you tried to get pregnant?

    [ ] yes [ ] no

17. If you have tried to become pregnant, how long did you try before becoming pregnant or discontinuing the attempt _____

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Fertility Questions

(if you are female, go on to next page)

18. Have you fathered any children?

[ ] yes [ ] no

If yes, how many _____

19. Have you tried to have children and been unable?

[ ] yes [ ] no

20. If you have tried to father any children, how long did you try before causing a pregnancy or discontinuing the attempt _____

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21. Do you have any unrelated (unrelated to FD or MAS as far as you know) medical problems?

[ ] yes [ ] no

If yes, please list them:

1. _____
2. _____
3. _____
4. _____
5. _____

22. List any other medications you take which have not already been mentioned:

1. _____
2. _____
3. _____
4. _____
5. _____

END